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## **Social support, coping, and positive perceptions as potential protective factors for the well-being of mothers of children with intellectual and developmental disabilities.**

**Objectives;** Behavioural and emotional problems exhibited by children with intellectual and developmental disabilities (IDD) have been identified as significant stressors for family members in both cross-sectional and longitudinal research. However, there is variability in the extent to which family members are affected by behavioural and emotional problems. In the present study, we explored whether perceived social support, positive perceptions, or coping style explain some of this variability and specifically whether these three variables function as protective factors.

**Methods;** One hundred and thirty eight mothers of children aged between four and 18 years old with IDD participated in a cross-sectional survey.

**Results;** Using moderated multiple regression models, we found consistent evidence that perceived social support functioned as a protective factor – affecting the relationship between child behavioural and emotional problems and maternal depression, life satisfaction, and positive affect. There was no evidence that coping and positive perceptions acted as a protective factors.

**Conclusion;** Building social support through parental interventions, especially in families of children with behavioural and emotional problems, may result in improved well-being for mothers of children with IDD.

**Key words:** intellectual disability, developmental disability, autism, mothers, psychological well-being, support, coping, positive perceptions

## Introduction

Mothers of children with Intellectual and Developmental Disabilities (IDD) show increased levels of stress when compared with other mothers of children without IDD (Emerson, 2003; Hastings & Beck, 2004). However, it is also evident that not all mothers are highly stressed. Totsika, Hastings, Emerson, Lancaster and Berridge (2011) found that 60% of mothers of children with IDD did not report having clinical levels of emotional problems. Clear contributing factors to this variation in stress are child behavioural and emotional problems. Previous research has shown child behavioural and emotional problems to be a risk factor for lower levels of psychological well-being among mothers (Baker et al., 2003; Blacher & McIntyre, 2006; Emerson, 2003, Hastings, 2003; Lewis et al., 2006; Lecavalier et al. 2006; Hastings & Brown 2002; Saloviita, Itälinna, Leinonen et al., 2003), and this risk factor has been identified in longitudinal studies as a significant predictor for an increase in maternal problems over time (Baker et al., 2003; Herring et al., 2006; Lecavalier, Leone, & Wiltz, 2006; Zeedyk & Blacher, 2015).

Despite the relationship between child behavioural and emotional problems and maternal well-being consistently shown in research, there is evident variability in the maternal responses to their child's behavioural and emotional problems; some mothers report emotional difficulties, and some do not. Theoretically, factors that are associated with positive outcomes may mediate or moderate this relationship, potentially explaining the variability in the outcomes.

A mediator specifies how (or the mechanism by which) a given effect occurs (Holmbeck, 1997; Baron & Kenny, 1986; James & Brett, 1984). Stated more simply, 'the independent variable causes the mediator which then causes the outcome' (Shadish & Sweeney, 1991, p. 883). A moderator 'interacts with a predictor variable in such a way as to have an impact on the level of a dependent variable' (Holmbeck, 1997, p. 599). In studies on

parental stress in IDD literature, many child characteristics (such as behavioural and emotional problems) and parental resources variables (such as social support) have been explored. However, typically only the main effects of predictor variables on parental psychological well-being have been addressed, thus researchers have rarely looked beyond a simple main effect relationship between risk variables and parental well-being.

In a small number of studies, mediated and moderated relationships have been explored. Researchers found the level of social support experienced by mothers of children with IDD had a moderating effect on the relationship between key variables, such as child behavioural problems and level of parental stress (Plant and Sanders, 2007). Social support was also found to be a moderator between stressors (life events and parenting stress) and negative outcomes such as depression, and social isolation (Dunn, Burbine, Bowers, & Tantledd-Dunn, 2001). Coping style (e.g., adaptive and maladaptive) has been found to be a moderator between stressors (life events and parenting stress) and negative outcomes such as depression, and social isolation (Dunn et al., 2001).

The main effects of variables related to child behavioural and emotional problems and positive or negative well-being outcomes should be considered when identifying protective factors, thus exploring these relationships further. Protective factors are defined in terms of their effect on reducing negative outcomes in the context of exposure to risk (Fergus & Zimmerman, 2005; Brook, Whiteman, Gordon, & Cohen, 1986; 1989). The concept of protection has been refined in a wider context in the literature relating to risk and resilience. Protective processes have been defined as “factors that modify the effects of risk in a positive direction” (Luthar & Cicchetti, 2000, p.3). Three levels of protective factors are generally widely accepted across the literature; individual level (e.g. positive temperament, self-esteem, self-efficacy, cognitive factors, coping strategies, social skills), family level (family cohesion,

warmth, emotionally responsive care-giving, parent-child relationships) and community level (peer networks, supportive communities and the school environment).

In main effect studies coping style and social support have been identified as having an impact on parental well-being. A passive emotion-focused coping style (such as wishful thinking, self-blame, distancing, and self-control) has been found to have a negative relationship with adaption or well-being (Dykens & Hodapp, 2001; Smith, Selzer, Tager-Flusberg, Greenberg, & Carter, 2008). Generally, parents who report using problem solving coping styles also report more positive adjustment outcomes and lower levels of parenting stress (Abbeduto et al, 2004; Glidden, Billings, & Jobe, 2006; Smith et al. 2008). Therefore, previous literature suggests the type of coping style used can account for some variation seen in parental psychological outcomes.

Similarly, a parent's perception of the level of received social support has been shown to have an impact on psychological outcomes. Parents of children with IDD who experience social support from their partners, family, friends, and social networks reported less stress and depression and generally more positive adjustment outcomes (e.g., Abbeduto et al, 2004; Hassall & Rose, 2005; Plant & Sanders, 2007; Glidden et al., 2006; Asberg, Vogel & Bowers, 2008). In this study, we will test another potential protective factor (positive perceptions), coping style, and perceived social support to develop further understanding of how these variables function in their relationship with child behavioural and emotional problems and maternal well-being.

When exploring factors associated with increased maternal well-being as an outcome, positive perceptions regarding having a child with IDD have been found to act as a protective factor amongst parents and caregivers. Werner and Shulman (2013) found the strongest predictors of subjective well-being in caregivers of individuals with ASD were self-esteem

and positive meaning in caregiving. Lickenbrock, Ekas, and Whitman (2011) found mothers who reported higher levels of positive perceptions of their child also reported higher levels of positive interactions with their spouse and higher levels of well-being. This suggests positive perceptions may act as a protective factor; however, existing research is limited to the exploration of main effects. Although positive perceptions may have main effect relationships with parental outcomes, there is also the potential theoretically for positive perceptions to act as a protective factor (Hastings & Taunt, 2002).

In the present study, three potential protective factors - social support, coping strategies, and positive perceptions of mothers of children with IDD - were explored. Previous research into coping styles and social support as protective factors is minimal, and in addition the literature has not fully explored positive perceptions as a protective factor. We hypothesised that these three factors would work as moderating/protective factors affecting the relationship between child behavioural and emotional problems and well-being outcomes in mothers of children with IDD. If either of these factors does work as a protective factor, we would expect that mothers exposed to high levels of child behavioural and emotional problems will report lower levels of stress and other problems if they also report positive perceptions, higher levels of social support and increased positive coping. In addition, the well-being of mothers exposed to lower levels of child behavioural and emotional problems would be less affected or unaffected by their positive perceptions, coping or social support.

## **Method**

### ***Participants***

The participants were 138 mothers (129 biological mothers, four adoptive mothers, two foster mothers, one step-mother) of children aged between four and 18 years old ( $M = 10.11$ ,  $SD =$

4.11) with IDD. The mothers' age ranged from 23 to 57 years ( $M = 39.42$ ,  $SD = 7.33$ ); 107 of the mothers were currently married or living with a spouse or partner, and 138 of the children lived permanently in the family home. The children who did not live permanently with their mother as the primary carer (i.e., those children who lived in a residential service or elsewhere some or all of the time) were excluded from the study.

22% of mothers were educated to University level and 16% had no formal educational qualifications (does not have secondary school qualifications usually obtained at age 16 in the UK). Almost half (49%) of mothers had full or part time work outside of the family home. The majority of the children with IDD were male (66%), 37% had a diagnosis of autism (as reported by the mother), 23% had Down syndrome, and 11% had Cerebral Palsy.

### ***Measures***

Eight measures plus a demographic questionnaire were utilised in the present study; all measures were completed by the mother of the child with IDD.

#### ***Demographic Questionnaire.***

Demographic information was gathered using a questionnaire developed by the research team (see Participants). A Total Disability Severity Index was created from four questions: whether the child had sensory problems, epilepsy, mobility problems, or any other health problem. Each were coded as 0 (*not present*), or 1 (*present*). Therefore, the new variable reflecting additional disabilities ranged from zero (*no additional disabilities*) to four.

#### ***Maternal Psychological Well-being***

**Anxiety and Depression.** The Hospital Anxiety and Depression scale (HADS: Zigmond & Snaith, 1983) was used to measure the mother's mental health over the past seven days. The measure includes a total of fourteen items, with seven depression items

(e.g., 'I feel as if I am slowed down') and seven anxiety items (e.g., 'I get sudden feelings of panic'). The total scores of the two subscales were used to assess depression and anxiety dimensionally. The HADS has been used with community samples of parents of children with disabilities (e.g., Hastings et al., 2005). The HADS has shown good psychometric properties (Hastings et al., 2005) and statistically good levels of reliability when used with mothers of children with IDD, with internal consistency coefficients between .79 and .84 for maternal anxiety (Hastings & Brown, 2002; Hastings, Daley, Burns, & Beck, 2006) and .78 for maternal depression (Jones, Hastings, Totsika, Keane, Rhule, 2014). In the present sample, Cronbach's alpha coefficients were .80 for depression and .82 for anxiety.

**Life Satisfaction.** The Satisfaction with Life Short Scale (Diener, Emmons, Larsen & Griffin, 1985) assesses the respondents' satisfaction with their life as a whole. The scale consists of five items which ask respondents the degree to which they agree with statements, such as, 'In most ways my life is close to my ideal', and 'I am satisfied with my life'. The responses are measured using a seven-point Likert scale ranging from, 1 (*strongly disagree*) to 7 (*strongly agree*), and a higher score is indicative of greater life satisfaction. The Satisfaction with Life Short Scale has been tested recently with mothers of children with IDD and was found to have a good Cronbach's alpha coefficient of .81 (Cohen, Holloway, Dominguez-Pareto & Kuppermann, 2015). In the present study, the Cronbach's alpha coefficient was .87.

**Positive Affect.** The Positive Affect Scale (PAS) is a ten-item subscale from the Positive and Negative Affect Schedule (PANAS: Watson, Clark & Tellegen, 1988). Participants were asked to report their feelings in the present moment responding to ten items (e.g., excited, strong, enthusiastic, inspired, and determined) by selecting a response from a five-point scale. The five-point scale ranged from 1 (*very slight or not at all*) to 5 (*extremely*). A total score is



then calculated by summing the scores on the ten items, in which a high score is indicative of a high positive affect. In the present study Cronbach's alpha coefficient was .91.

### *Maternal Moderator Variables*

**Social Support.** The Short Support Functions Scale (Dunst, Trivette & Deal, 1988) assesses different types of perceived support from other people (e.g., 'Someone to talk to about things that worry you', 'Someone to help take care of your child', 'Someone who loans you money when you need it'). The items ask about help in financial, emotional, instrumental, and informational support. The respondents answer 12 items in the short form version, which was used in this study, on a five-point Likert scale with answers ranging from 1 (*never*) to 5 (*quite often*). Higher overall scores indicate higher levels of perceived support by the respondent. In the present study, the Cronbach's alpha coefficient was .88.

**Coping.** Maternal coping was measured using the Shortened Ways of Coping Questionnaire (Hatton & Emerson, 1995). This 14-item has two subscales; seven questions on wishful thinking (e.g., 'I wish that I could change how I feel', 'I have fantasies or wishes about how things might turn out') and seven questions on practical coping (e.g., 'I try to analyse the situation in order to understand it better', 'I make a plan of action and follow it'). The respondents are asked to answer each statement to indicate how often they use that coping mechanism on a four-point scale ranging from 1 (*not used*) to 4 (*used a great deal*). The two subscales are summed separately to provide a wishful thinking coping score (emotion-based coping style) and a practical coping score (problem focused coping style). The Cronbach's alpha coefficient was .79 for practical coping and .85 for wishful thinking.

**Maternal Positive Perceptions.** Mothers' perceptions of the positive contributions their child with IDD has made to them and their family were measured using the Positive

Contributions Scale from the Kansas Inventory of Parental Perceptions (PCS: Behr, Murphy, & Summers, 1992). The PCS includes 50 items reflecting the impact on the mother (e.g., 'My child is...' 'The reason my life has better structure', 'Responsible for my learning patience'), and on the wider family (e.g., 'Bringing the family closer together', 'Helping other family members to become more understanding of other people') as well as positive characteristics of the child themselves (e.g., 'Kind and loving', 'Fun to be around'). The items are rated on a four-point agreement scale ranging from 1 (*strongly disagree*) to 4 (*strongly agree*). For the current study, a total score was calculated; a higher score indicated a higher level of perceived positive impact. In the current study, the Cronbach's alpha coefficient for the PCS total score was .93.

#### *Maternal Exposure to 'Risk'*

**Child Behavioural and Emotional Problems.** The behavioural and emotional problems of the child with IDD were measured using the Reiss Scales for Children's Dual Diagnosis (Reiss & Valenti-Hein, 1990). The 60 items cover ten sub-domains (attention deficit, anger, anxiety/self-control, conduct disorder, depression, autism/pervasive, psychosis, poor self-esteem, somatoform behaviour and withdrawn behaviour) contributing to a total score. Mothers were asked to score each item on a three-point scale 1 (*no problem*), 2 (*problem*), or 3 (*major problem*). The Reiss Scales have been previously shown to have good internal consistency with a Cronbach's alpha coefficient of .91 for the total score (Reiss & Valenti-Hein, 1994). In the present study, the Cronbach's alpha coefficient for the total score was .95.

#### ***Procedure***

The participants in the present study were 138 mothers from a larger survey which included 142 families of children with IDD (Hastings, Beck, & Hill, 2005). Four mothers were

excluded from this study due to their child not living full time with them. The families were recruited through Special Educational Needs schools in North Wales and North West England that focused on the education of children primarily with severe intellectual disability. Information packs were distributed to parents via schools for children with intellectual disabilities; these included a response form and a business reply envelope addressed to the project team. Upon response forms being returned, a questionnaire pack and consent form were sent to the primary parental caregiver via post, marked for return to the University. One hundred and eighty-eight mothers were sent questionnaires. The final response rate for mothers was therefore 76%. Mothers were paid a voucher for returning the questionnaires to the research team.

In each scale, when a missing value was found, this was inputted as a mean average of the other scores given in that particular subscale/scale by that participant. This followed the recommendation of each measure; for example, the REISS guidance suggests if two or more items are missing from a subscale, that participants' responses must be excluded from the REISS dataset.

## **Results**

To assess social support, coping (both wishful thinking and practical coping styles), and positive perceptions as moderators, multiple regression analyses were conducted for each of the four maternal psychological well-being measures (anxiety, depression, life satisfaction, positive affect) (see Table 1.). Relevant demographic variables (some dichotomised such as maternal education, maternal employment) were selected for inclusion in each of the four analyses if they had significant bivariate relationships (via correlations or *t*-tests) with maternal outcomes. Mothers of children with IDD who were married or living with a partner had significantly lower anxiety than those mothers who were not ( $t(137) = -2.21, p = .029$ ).

Mothers of children who had Cerebral Palsy had lower levels of life satisfaction ( $t(137) = -2.03, p = .044$ ) compared to mothers in the study whose children did not have Cerebral Palsy.

Pearson's correlations showed older mothers reported lower anxiety than younger mothers ( $r = -.22, p = .011$ ). Mothers who reported their child as having more additional disabilities had increased PAS positive affect scores compared to mothers who reported fewer additional disabilities ( $r = .17, p = .042$ ).

The key predictor in each analysis was child behavioural and emotional problems and four moderators (type of coping style [a. wishful thinking, b. practical coping], perceived social support, and positive perceptions) were entered individually both as a main effect and as an interaction variable with child behavioural and emotional problems. The 'PROCESS' custom dialogue box (Hayes, 2012) was installed into SPSS for the moderated multiple regression analyses. Multicollinearity issues between variables were checked using the Variance Inflation Factor (VIF); and the variables showed no multicollinearity issues (all values  $< 10$ , average  $> 1$ , tolerance  $> 0.1$ ) (Bowerman & O'Connell, 1990; Myers, 1990). Predictor variables were automatically mean-centred when using PROCESS (the variable mean is subtracted from each value of the variable).

[INSERT TABLE 1 NEAR HERE]

Following the recommendation by Aitkin and West (1991), a simple slope analysis was conducted to aid interpretation of the three significant interactions (see values in bold on Table 1). Plots were derived from the PROCESS output and show the relationship between high versus low child behaviour and emotional problems and the maternal outcome, with the moderator at three values- high, mean and low.

Social support was the only proposed moderator which was associated with statistically significant moderator/interaction terms. This occurred in three models: life satisfaction ( $p = .042$ ), depression ( $p = .036$ ), and positive affect ( $p = .011$ ). All three slope

analyses show a classic protective factor pattern: better outcomes at high levels of risk (higher levels of behavioural and emotional problems) when the moderator is present at higher levels (i.e., a lack of association between child behavioural and emotional problems and maternal outcomes when social support levels were high).

Child behavioural and emotional problems were a significant independent predictor in two of the four models (anxiety and depression) when wishful thinking coping was the moderator. Wishful thinking coping was also a significant main effect independent predictor in all of the four models: anxiety ( $p < .001$ ), depression ( $p < .001$ ), life satisfaction ( $p < .001$ ), and positive affect ( $p = .003$ ). There was no evidence that wishful thinking coping acted as a protective factor.

Child behavioural and emotional problems were a significant independent predictor in all four models when practical coping was included. Practical coping was a significant independent main effect predictor in three of the four models (life satisfaction, depression and positive affect). There was no evidence that practical coping acted as a protective factor.

Child behavioural and emotional problems was a significant independent predictor in two of the four models (anxiety and depression) when positive perceptions was included. Positive perceptions were a significant main effect independent predictor in two of the four models (life satisfaction and positive affect). There was no evidence that positive perceptions acted as a protective factor.

[INSERT FIGURE 1 NEAR HERE]

[INSERT FIGURE 2 NEAR HERE]

[INSERT FIGURE 3 NEAR HERE]

## Discussion

Levels of social support consistently had a moderating effect on the relationship between child behavioural and emotional problems and maternal well-being (depression, life

satisfaction and positive affect). These were classic protective effects – when social support was at high levels, there was no association between child behavioural and emotional problems and maternal well-being. These findings are consistent with previous research which, have demonstrated social support has a moderating effect on the relationship between key variables, such as child behavioural problems and level of parental stress (Plant and Sanders, 2007).

We found no evidence that practical or wishful thinking coping or positive perceptions functioned as protective factors. However, each had significant main effect relationships with maternal well-being. Similar main effect associations between maladaptive coping and maternal well-being have been found previously (Hastings et al., 2005). These findings suggest that coping and positive perceptions have a positive impact on mothers' well-being, regardless of the level of their child behavior problems. Therapeutic interventions to develop more positive coping skills and to elucidate families' positive experiences may be useful avenues for practice and research.

There were several limitations to this study that need to be taken into account when interpreting these results. First, the generalizability of this sample to other studies may be limited, as most mothers were either married or living with a partner, and a relatively low proportion for the UK had a university education. The mean age of mothers was 39.42 ( $SD = 7.33$ ) years, therefore, it is unknown if this sample is reflective of younger or older mothers. The mothers in this study were recruited through Special Educational Needs Schools in North Wales. Therefore, this sample does not include experiences of mothers who have children in mainstream education. The experiences and views of mothers may vary depending on the school their child is attending, and in which area of the UK. Therefore, this poses a limitation for generalisability of this study.

In addition, this study was dependent on mothers' self-report data and did not have any independent assessments leading to a potential problem of source variance. To address this, future research will need to incorporate independent or multiple informant approaches for key constructs to address this potential limitation (e.g., child behavioural and emotional problems). Finally, the study is limited by its cross-sectional design. This is problematic since temporal precedence has not been established. For example, it may be the case that mothers with higher levels of psychological distress are less able to find support, or experience more support. Protective factors, such as coping and support, are often dependent upon personal circumstance and therefore measuring them at a single time point is not representative of the development, or idiosyncratic changes over time. Previous research has suggested moderators could vary throughout a person's life (Olsson & Hwang, 2008; Ellingsen, Baker, Blacher & Crnic, 2014). Future research could also explore differences between mothers and fathers and which factors may act as moderators for fathers of children with IDD.

Our findings have potential practical implications. In particular, it would be beneficial to directly try to monitor perceived social support in mothers of children with IDD, and to encourage mothers to find support in local support groups provided by charities or local services, to improve their well-being. Also, it could be useful to encourage mothers to find support in local support groups provided by charities or local services, to improve their well-being (e.g. Lunskey et al. in press). This study compared two community based interventions for parents of adults with autism spectrum disorder and developmental disabilities. It was found parents in the information group reported no difference in psychological distress whereas parents in the mindfulness group did report significant reductions in psychological distress, this was also maintained at the 20-week follow-up.

Secondly, interventions to directly improve the social support available for mothers could be explored as a way of improving well-being especially in families with a child with high levels of behavioural and emotional problems.



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Table 4. Moderated Multiple Regression Analyses Models for the Four Maternal Psychological Well-being Measures.

[illegible]

Age of mother			-.055	.159				
Cerebral Palsy present	-4.301	<b>.007</b>						
Living with partner/spouse			.549	.089				
Child behavioural and emotional problems (centred)	.001	.971	.047	<b>.008</b>	.039	<b>.010</b>	-.056	.152
Coping wishful thinking (centred)	-.958	<b>&lt;.001</b>	.390	<b>&lt;.001</b>	.386	<b>&lt;.001</b>	-.502	<b>.003</b>
Coping wishful thinking x Child behavioural and emotional problems (interaction)	.004	.517	-.001	.867	<.001	.904	.007	.323
<hr/>								
Moderator- positive perceptions	<u>Life Satisfaction</u> R = .371, R <sup>2</sup> = .138 F= 4.786, n = 125		<u>Maternal Anxiety</u> R = .479, R <sup>2</sup> = .230 F= 7.272, n = 128		<u>Maternal Depression</u> R = .442, R <sup>2</sup> = .195 F= 10.204, n = 130		<u>Positive Affect</u> R = .507, R <sup>2</sup> = .257 F= 10.795, n = 130	
<u>Variable</u>	$\beta$	p	$\beta$	p	$\beta$	p	$\beta$	p
Additional disabilities							.647	.248
Age of mother			-.067	.138				
Cerebral Palsy present	-3.840	<b>.038</b>						
Living with partner/spouse			.743	<b>.046</b>				
Child behavioural and emotional problems (centred)	-.055	.137	.090	<b>&lt;.001</b>	.074	<b>&lt;.001</b>	-.066	.083
Positive perceptions (centred)	.067	<b>.037</b>	.012	.464	-.029	.069	.172	<b>&lt;.001</b>
Positive perceptions x Child behavioural and emotional problems (interaction)	.003	.063	<.001	.842	<.001	.620	.003	.161

Note: Significant (p < .05) associations between variables are in boldface.



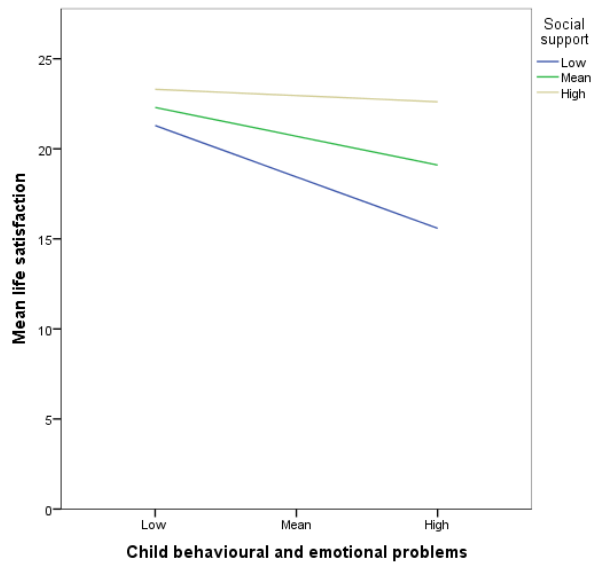


Figure 1. Simple slope graph for life satisfaction as the outcome variable. There was a negative relationship between child behavioural and emotional problems and life satisfaction at mid ( $p = .008$ ) and low ( $p < .001$ ) levels of social support, but not when social support was high ( $p = .704$ ). However, higher levels of social support were associated with less of a decrease in life satisfaction.

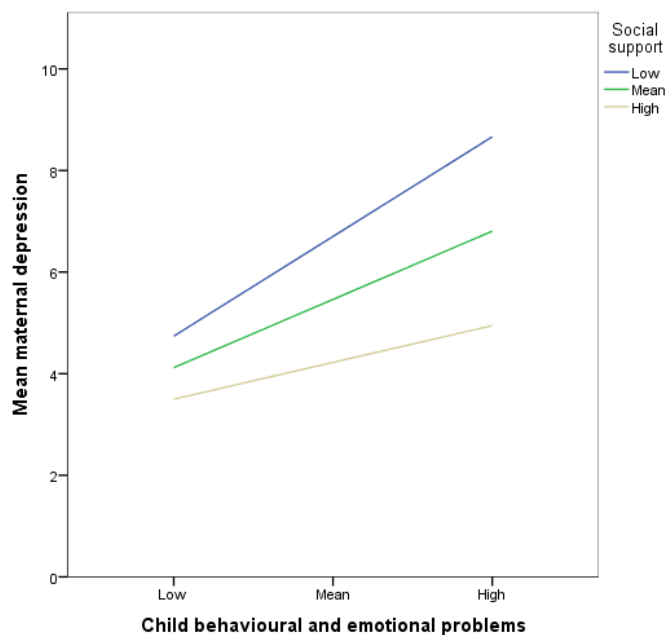


Figure 2. Simple slope graph for maternal depression as the outcome variable. There was a positive relationship between child behavioural and emotional problems and depression at mid ( $p < .001$ ) and low ( $p < .001$ ) levels of social support, but not when social support was

high ( $p = .094$ ). However, higher levels of social support were associated with less of an increase in depression.

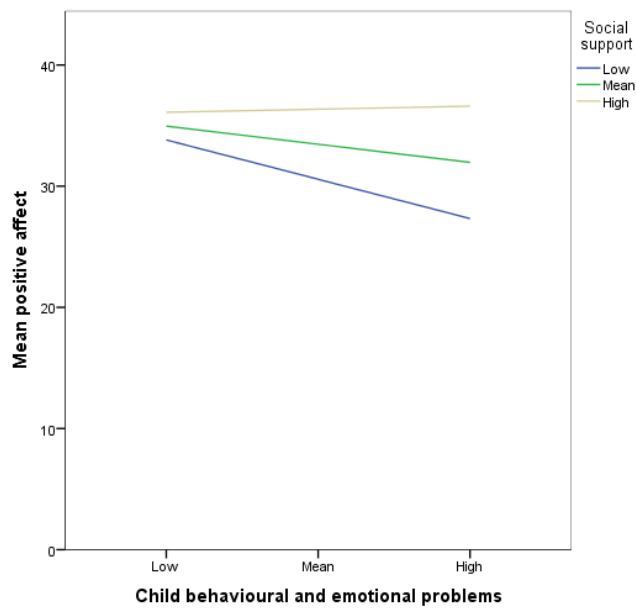


Figure 3. Simple slope graph for positive affect experienced by mothers of having a child with IDD as the outcome variable. There was a negative relationship between child behavioural and emotional problems and positive affect at mid ( $p = .026$ ) and low ( $p < .001$ ) levels of social support, but not when social support was high ( $p = .805$ ). However, higher levels of social support were associated with a slight increase, and no decrease in positive affect.

